From Politics of Science to Evidence-based Activism

> Any method of management that implies the supposition-anticipation-suggestion of stupidity or infantilism of the individuals that constitute this society should be excluded; for, if they are defined as stupid or infantile, democracy itself can only be defined as manipulation, a modern new way of leading the flock. (Stengers & Ralet, 1997: 223)

Can there be a politics of science? And what would such a thing mean? Natural sciences, for instance, seem to be fairly detached from everyday political quarrels. The only moment when this type of science enters the political scene seems to be to restore order or to present the facts about a certain subject. First the facts, then a political discussion about what values we can attach to them. From this perspective the role of citizens is minimum: they are there to listen to the experts.

But perhaps there is a room for different approach if we turn it around. Certainly, science has become so big and important that its institutions itself require policy plans. The question is then: how do we organize science? Is every scientific research program one that we want to support and pursue? This opens the road to some involvement of political discussion within science. But who should be involved? Should it be the scientists themselves deciding what to do? Or can there be a form of 'citizen science', in which the public is actively involved?

1. The societal role of scientists

Although scientists are traditionally perceived as living in ivory towers, completely detached from society, such an image has recently become problematic. In the last half century there seems to be a rise of interventions of scientists in society, fighting against forms of misuse and derailment of science. First of all you have individual scientists getting involved by publishing about it. One such a case was Jacob Bronowski warning for an age of science after the atomic bomb. He proposed, for instance, that the rubbles of Nagasaki should be preserved, and that future conferences on disarmament and other issues should be held at that spot. "[O]nly in this forbidding context could statesmen make realistic judgments of the problems which they handle on our behalf." (Bronowski, 1965: xiv)

A second variety is a collective of scientists uniting under a single banner, such as the Club of Rome, founded in 1968. This club consists of group of scientists concerned with the future of humanity, especially related to ecological problems resulting from our highly technological society model. Or another example was the British Society for Social Responsibility in Science (BSSRS), that came into being in 1969, and had a magazine called *Science for People*. A more recent shape of this idea sprung up as the call for more scientists in parliament: our politics is so ignorant because our politicians are so ignorant of science. In a similar fashion, Mark Henderson, author of *The Geek Manifesto* (2012) pleas for 'geek activism': because politicians fail to take science into account, geeks must "create a political cost for failing science." (Henderson, 2012: 29)

The political side of science also came to the foreground due to the explosion of research projects within the social sciences concerning science policy. The academic scene has witnessed the birth of disciplines such as the Sociology of Scientific Knowledge (SSK) and Science and Technology Studies (STS). They mainly argue that science has never been a

detached, disinterested practice as often portrayed, but that political struggle and social values are inherent to it. Just to give one famous example, the sociologists Harry Collins and Trevor Pinch claim, in their book *The Golem: what everyone should know about science* (1993), that science is just a human product, and thus has to be supervised like any other institution.

However, most of these models presuppose that the 'public' of science communication is a passive, ignorant or even anti-scientific mass. This so-called 'diffusion' model of science communication portrays the public as passively waiting to be informed, and its criteria of success seems solely to be to let the lay audience agree with the experts (Clark & Illman, 2001: 9). Such a perspective can be questioned, as has been done by James Surowiecki in his book *The Wisdom of Crowds* (2004). Rather than following the popular idea that "groups tend to make people either dumb or crazy" (2004, XV), we should open our eyes for instances when the knowledge of the crowd outweigh that of the individual expert.

The question whether such a 'wisdom of the crowd' exist, is crucial. It can lead to a radical different appreciation of what public engagement in science could mean. Rather than stating that activists at best could repeat available scientific data, one can image that activists are and should be contributing to the scientific discussions themselves. Similar to two different perspectives on democracy, one could ask whether public engagement with science is either necessary because individuals have the right to participate in any discussion whatsoever, or whether "we have it because democracy is actually an excellent vehicle form asking intelligent decisions and uncovering the truth?" (*Ibid*.: 262) Can citizens do science, or can they even do it better than the scientists themselves? Such a perspective is central in the phenomenon of *citizen science.*

2. Citizen science

Citizen science can be defined as "a form of research collaboration involving members of the public in scientific research projects to address real-world problems." (Wiggins & Crowston, 2011). In this sense it consists of a more radical way in which society can be involved in scientific controversies. The claim is that citizens themselves should not only participate in the discussion concerning the political consequences of science, but also in the technical discussion of the scientific content itself. The idea is that citizens can produce scientific data of equal value than the data collected by the scientists. Citizen science often involves scientific work on massive scales unattainable or too labour intensive for individual research teams and has been booming in the recent decades. Many projects take advantage of new technological innovations an possibilities of the digital age, such as the internet, which make such a massive scale projects possible. In this sense it can be described as "a form of crowdsourcing applied to science" (Wiggins & Crowston, 2011).

Citizen science, however, exists in many forms. The most simple and basic example is the counting of birds or bees in people's private gardens. This might sounds trivial, but the *eBird* database has been used in at least 90 peer-reviewed articles and book chapters (Bonney et al., 2014: 1436). The size of these projects can vary: from just a few students working on a local project to 60.000 observers, such as in the Audubon Society's Annual Christmas Bird Count. Another clear example is that of the 'Zooniverse', in which pictures of parts of the universe are shown to lay people which are ask to answer simple questions about it, such as 'how many arms does the spiral galaxy has?' Again, the data collected by this project has been used in numerous scientific articles.

Wiggins & Crowston (2011) propose the following typology of citizen science projects:

(a) *Action projects*: projects aimed to intervene in nature, such as the protection of a local creek. Such projects are often bottom-up and local in which scientists are mostly used as external consultants.
(b) *Conservation projects:* projects are aimed to conserve certain parts of nature, such as biodiversity or knowledge about local culture. It is occasionally linked with educational goals and aims to create volunteer stewardship and awareness.
(c) *Investigation projects:* projects aimed to collect data about a certain aspect of the physical environment. The earlier case of the recording of bee activity is a clear example. Knowledge production is central here, and the question whether the data is scientifically valid is a crucial question. Other examples are the 'Quantified Self' movement, in which participants collect data about all the aspects of a person's daily life, such as what they eat and how they feel, or a *ExCiteS* project in which the native population of Congo is used to map the local forests.
(d) *Virtual projects*: projects which are completely ICT-mediated, such as the earlier example of the *Zooniverse*. A similar example in the case of biology is *Foldit*, in which the structures of proteins are found based on mass participation. Again it is often aimed to produce scientific data, and makes use of validity-by-replication: the data to be interpreted, such as the photos of galaxies, often go through multiple reviews or ratings. An interesting example here is *23andMe*, a for-profit organisation which combines DNA-testing and direct-to-consumer genotyping with using this DNA-database to produce new scientific research (see Harris et al., 2013).
(e) *Education projects:* projects aimed to educate and enthuse citizens for a certain branch of science. It provides informal learning resources to citizens, such as toolkits, so they can learn what the science is really about. An example is the case of DIY-biology labs, discussed below, in which lay people can do simple biological experiments by themselves to learn what biology is all about.

For a full list of projects within Europe, see the White paper on Citizen Science in Europe

These projects are, thus, very diverse. However, one can still argue that they all come down to scientists using crowds to do the dirty work for them, although occasionally there are projects from the bottom-up. In fact, most of these project have an uncanny similarity to experiments done by Levenson et al. (2015) who trained pigeons to spot pathologies on breast cancer images. Humans do not seem to be crucial in such projects, and can even be replaced by mere computers. This is the case for Fondit@home or Rosetta@home, which aim to do similar scientific work by simply running a small program on your computer and, so, 'stealing' some of your CPU power for their projects.

In what sense are these forms of citizen projects really a new form of citizen participation in scientific controversies? Counting birds and bees does not seem very political and revolutionary, especially if you can in principle train them to count each other. On the contrary, such citizen science is a clear form of 'free labour' for companies such as 23andMe, who are using your data to make profit (Levina, 2010). However, there is in fact a class of citizen science projects which lead to what has been called *evidence-based activism*: cases where citizens do take matter into their own hands and produce knowledge to *correct* or *adjust* the mainstream scientific consensus (Rabesharisoa et al., 2014).

3. Evidence-based activism?

Although citizen science brings science and society closer together, a real blurring of the distinction between scientist and citizen, expert and lay person, takes place in more radical cases of citizen participation in scientific controversies. From the 70s there have been clear cases of what could be called 'evidence-based activism', namely the participation of lay persons and patient organisations in the production of scientific knowledge. The main question they pose is: should we just equate experts with scientists? For there is a danger in doing so: thinking that scientists of various disciplines are experts on *every* field simply by being a 'scientist'. There is no guarantee for that, because sciences can be very diverse and there is no such thing as one, unified scientific method (Collins & Evans, 2004: 260). It is an error to judge experts solely on basis of credentials, rather than merits. One famous historical example is the exclusion of the knowledge present in local sheep farmers in the UK, after the Chernobyl disaster which resulted in a radioactive cloud heading towards the UK. "Their criticisms were ignored, but were vindicated later when the experiments were quietly abandoned for the reasons that the farmers had identified. The farmers had expressed valid and useful specialist knowledge for the conduct and development of science, but this was ignored." (Wynne, 1992: 287)

There are, however, instances where patient organisations intervened in scientific controversies and were not ignored. This has been the case in AIDS activism, such as the *AIDS Coalition to Unleash Power* (ACT UP) movement, where some of its members succeeded in presenting themselves as credible within the arena of expertise (Epstein, 1996). They pleaded, for instance, for more diverse samples in the testing of experimental medicines for AIDS, not only on moral grounds, but also on scientific grounds. More diverse samples are a better representation of the messy reality we do live in. Arguments of theirs have been published in scientific journals and presented at scientific conferences (e.g. Delaney, 1989). They were able to influence which studies would receive funding and could even alter the definition of AIDS.

Although ACT UP was mainly active in the USA, a clear European example is the *Association française contre les myopathies* (AFM) created in 1958. Myopathy is a rare muscular disease, for which no cure has been found. Rather, those affected by it used to be seen as 'defects of Nature'. The AFM, although originally founded to help patient manage their illness, has redirected its goals to research and clinical efforts to combat the disease. It produced 'experts by experience': members of this organisation, often family of the patients, who collected, formalised and circulated patients' experience as a legitimate body of "experiential knowledge" (Rabesharisoa et al., 2014: 3). They used help lines, internet forums, speech groups, a television show (a *téléthon*), but also real scientific research and recognized social research methods to influence and stimulate the scientific research related to the disease. They made themselves part of the networks of expertise, and so changed the science of their disease as well as its societal perception.

A third example is DIYbio (Do-It-Yourself biology), a network of amateur biologists, which came into being around 2008. DIY-biologists want to contribute to biology from outside the university by creating their own private labs. Sometimes these labs are built in basements, garages or kitchens, but there are at least 14 community labs in the USA (Grushkin et al., 2013). Examples in Europe are *La Paillasse* in Paris, *BiologiGaragen* in Copenhagen, or *ReaGent* in Ghent. The goal of DIY-biology is not only to educate the lay audience, but also to create valid scientific data and biological products themselves. In 2014, for instance, Andrew Hessel, a

Canadian futurist, initiated the 'Pink Army Cooperative', which aimed to bypass the multibillion-dollar pharmaceutical companies in finding a cure for breast cancer. Instead the people should do it themselves, in their basements or kitchens, using the new tools resulting from developments within genetic engineering and synthetic biology (Nelson, 2014: 152). Such is also the ambition of Nina DiPrimio at the Perlstein Lab, San Francisco. Under the banner of "Leave No Mutation Behind" the lab aim to find 'orphan cures' for rare diseases for which big pharma has no interest.

The ambitions of DIY-biology are, however, more than just finding cures. As the sociologist Alessandro Delfanti writes in his book on biohacking, the goals of these activists are not "confined to problems of access to information and knowledge, but includes battles over the very shape of science's institutions as well as over public participation in and control of scientific knowledge production." (Delfanti, 2013: 10-11) Connected to the 'biopunk' and 'biohacking' movements, DIY-biology is linked to debates about property rights and patents: it often calls for open source and open science, similar to themes in cyberpunk and hacker communities. Many of the above mentioned examples aim to offer open source cures for the diseases. One example outside the medical sphere is the Glowing Plant project, which aim to create a glowing *Arabidopsis thaliana* plant which should replace street lights in the future and so reduce CO_2-emissions. Using crowdsourcing tools such as Kickstarter, the project's founders already raised $484,000 in 2013 and sparked quite a controversy about their project (Callaway, 2013).

What do these movements have in common?[1] One possibility is what the anthropologist Paul Rabinow calls 'bioscociality': their identity is formed around a certain scientific fact about them, such as a disease or medical condition, rather than culture or ideology (Rabinow, 1999). They refuse to be a 'passive' audience, waiting to hear the scientific truth about their identities, but try to participate in its construction and in the understanding of their medical condition. In this sense, these are clear examples where science and society interact, namely by opening the door to 'experiential knowledge' in areas of scientific research which are dependent on societal processes. Here we enter the area of 'hybrid forums': cases where a diverse group of stakeholders come together to discuss the technical options involving the collective in which they live. They are hybrid due to the fact that the groups are heterogeneous and might include experts, politicians, technicians and laypersons, and because the questions and problems raised are not merely scientific questions, but do also have ethical, political and economic aspects (Callon et al., 2009: 18).

However, this should not be misunderstood as a plea to include citizens everywhere as much as possible, but rather to not exclude them without due consideration. Such a false conclusion can only be the result of an ambiguity in the concept of the 'public'. Traditionally one understands it as referring to every citizen within the nation state, as if one should consult everyone's opinion on the matter. That is not at stake here. Rather, the public is understood in a different manner, namely as the set of stakeholders for whom this specific scientific issue is a matter of concern. In this sense the public is not pregiven, but arises as a consequence of the controversy. Faced with a scientific controversy, actors will come forward and ask questions, and this will not only include scientists (see Dewey 1976). The claim is not that there is no real scientific expertise,

[1] There are a range of different examples of this evidence-based activism, such as ecology movements, antinuclear movements or cancer activists.

nor that we all are experts. Rather it is a plea to rethink who can ask the relevant questions and who can answer them, and how we can benefit from posing that very same question.

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*Science for the People*was an organization in the United States in the 1970s, aimed to fight against all forms of misuse of science.